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ABSTRACT

This report discusses the accomplishments and challenges of the Vermont Self-Determination Project (SDP), a 3-year project designed to empower individuals with developmental disabilities to create the quality of life they desire for themselves and, by discovering and sharing their natural gifts and talents, to nourish and enrich both their own lives and those of their communities. To meet this goal, the SDP has worked collaboratively with people with disabilities and families to promote statewide systems change both to increase opportunities for choice and control and to decrease barriers to choice and control. The report is based on interviews conducted with SDP teams, other project staff, and individuals with disabilities and families of individuals with disabilities who have had some contact or involvement with SDP teams. The report addresses four areas: opportunities for self-determination at the individual level, systems change to promote self-determination, self-advocacy, and issues related to implementation of the SDP itself. For each area, there is a discussion of accomplishments and challenges. This is followed by a section addressing next steps that were identified during the course of the research, and a brief conclusion. Findings indicate SDP has made a significant contribution to comprehensive systems change. (CR)

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CONTRIBUTIONS OF THE VERMONT SELF-DETERMINATION PROJECT

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SELF-DETERMINATION IN VERMONT:

CONTRIBUTIONS OF THE VERMONT SELF-DETERMINATION PROJECT

This paper was generated as part of a "learning community" between the Vermont Self-Determination Project (SDP) and the Center on Human Policy. The intent of this learning community is to serve as a forum for discussion of issues and lessons, from a range of perspectives, related to implementation of self-determination in Vermont.

The SDP began as a 3-year initiative (January 1997-December 1999) funded by the Robert Wood Johnson Foundation. The mission of the SDP is to "empower individuals with developmental disabilities to create the quality of life they desire for themselves and, by discovering and sharing their natural gifts and talents, nourish and enrich both their own lives and that of their communities." As part of this, the SDP has worked collaboratively with people with disabilities and families to promote statewide systems change both to increase opportunities for choice and control and to decrease barriers to choice and control.

An earlier paper, based on interviews conducted following the first year of the project, discussed issues and challenges related to implementing self-determination in Vermont. This paper builds on that, with a focus on accomplishments and challenges of the SDP after 3 years. At the same time, there is clear recognition that many of the accomplishments were not the result of the SDP alone, but of the SDP and many other individuals and

groups, working on their own and in collaboration with one another. It is also acknowledged that the accomplishments of the SDP did not begin with this 3-year initiative, but built upon ongoing efforts of other stakeholders within the state. Finally, it is recognized that the "next steps" and challenges cannot and should not be addressed by the SDP alone.

The report is based on interviews conducted with SDP teams, other project staff, and individuals with disabilities and families of individuals with disabilities who have had some contact or involvement with SDP teams. In addition, the perspectives of a variety of other people, including staff of the Division on Developmental Disabilities, guardians, case managers, and agency directors, were gathered through interviews and an e-mail survey. Interviews and the e-mail survey were conducted in the Summer and Fall of 1999. All names used in this report are pseudonyms.

The report addresses four areas: opportunities for self-determination at the individual level, systems change to promote self-determination, self-advocacy, and issues related to implementation of the SDP itself. For each area, there is a discussion of accomplishments and challenges. This is followed by a section addressing "next steps" that were identified during the course of the research, and a brief conclusion.

OPPORTUNITIES FOR SELF-DETERMINATION AT THE INDIVIDUAL LEVEL

As a part of system-wide change, a major focus of the project was providing information about self-determination to individuals with disabilities and families, and facilitating pursuit of more choice and control in their lives. Some of the key accomplishments and challenges related to implementing self-determination at the individual level are discussed below.

Accomplishments Related to Promoting Opportunities for Self-Determination at the Individual Level

This section focuses on contributions of the SDP in promoting opportunities for self-determination for individuals with disabilities and families of children with disabilities. It includes brief stories to highlight some examples.

1. **There is increased awareness and knowledge about self-determination among people with disabilities and their families.** From the outset of the project, one of the central goals was providing information and resources about self-determination to individuals with disabilities and families. Team members and other project staff spent a significant amount of their time meeting with individuals with disabilities and families to talk about the idea of self-determination, as well as the role of the SDP. In addition, teams created informational materials about self-determination that were accessible to a wide range of people (e.g., use of

graphics, large print, absence of professional jargon). There was widespread agreement among others who were interviewed (besides project staff) that the SDP has made a significant contribution toward increasing knowledge and awareness about self-determination in the state.

2. **There are more opportunities for choice and control for some people with disabilities and some families of people with disabilities.** There is widespread agreement there are more opportunities for choice and control, at least for some people in Vermont, and that these are a result of the efforts of those involved with SDP and many others.

Many of the people interviewed felt that the SDP, working in collaboration with people with disabilities, families, guardians, and agency staff, made significant contributions in this regard. As one agency director commented, "The teams have directly helped some of our consumers and families to better shape their services." Through individual referrals, SDP teams assisted people with disabilities, family members, and others to move toward making significant changes in their lives and changes in the degree of choice and control they have over the supports they receive.

There are many ways that this change occurred, including agencies that changed to accommodate people's desires and needs (giving people more choice, options, involvement); people who chose to switch to another agency in order to find more responsive services (although, this was not always easy or possible due to lack of alternative agencies); and people who

chose to go "outside" of agencies to create different support options for themselves.

One of the major ways that the SDP contributed to increased choice and control for people was through its role in bringing people together with the focus person and/or family. As one team member commented, "Probably 90% of the work we do is to bring people together and get dialogue going." Teams helped arrange and facilitate meetings involving the person and/or family, relevant service system representatives (e.g., direct staff, case managers, administrators, etc.), and relevant people from other organizations or the community-at-large. Within the context of these meetings, the teams made an effort to ensure that the person's and/or family's voice was central. Through these meetings, people shared information and ideas, and worked together to implement changes.

In addition to the role of bringing people together, the teams contributed toward individual change in many other ways. For example, they helped identify priorities by facilitating person-centered planning processes. They also helped by contributing creative ideas, identifying resources, and answering technical questions. Sometimes the work of SDP teams supplemented that of agency staff who were interested in helping the person make changes, but did not have enough time. As one agency director explained, "Teams have been able to work with people at a level providers have difficulty doing due to work demands."

In other instances, teams worked with people to make changes where agencies had been resistant to such change. As one person noted, "Teams played a great role in helping people do some things that agencies had been telling people was impossible." Finally, the teams advocated for people by helping to ensure that their voice was central to all discussions and decisions.

One example of change is a story about Fred, in which the team's involvement resulted in changes in agency services for him.

At a young age, Fred was placed in Brandon Training School. Eventually he moved into a group home, and lived there until it closed. While at the group home, he developed a close relationship with one of the staff members, Christa, and her family. When the group home closed, Fred moved into their home.

Christa initially contacted the Self-Determination Project because of her frustration about trying to get some daytime supports set up for Fred through the designated agency. He previously had a daytime support person, but in the 10 months since that person left, he had no daytime supports. Christa felt that Fred was bored and upset with not having some meaningful daytime involvements, and that without consistent support, he had been losing some of his previously acquired abilities and was becoming more dependent on others.

There were other issues that Christa wanted to address, including lack of sufficient money to pay for thickeners that Fred needs for nutritional purposes; enhancing Fred's means of communication; and assisting Fred to get a regular amount of spending money on a regular basis from his representative payee.

The SDP team assisted by facilitating a person-centered planning process involving Fred, Christa, agency staff, Fred's guardian, and other friends of Fred. Christa reflected, "Once we started doing the MAPS (planning process), Fred started getting really excited." Following the MAPS, the agency reinitiated day services for Fred, hiring a person chosen by Fred and Christa who supports Fred in a variety of activities. The agency also figured out a way to pay for Fred's thickener through use of some other sources of money. And, they arranged for a communication assessment, which resulted in Fred getting a small communication device. Finally, as a way to address the issue with spending money, the team suggested using a private representative payee. Christa assisted Fred in getting one, and things are working well with the new arrangement.

Overall, Christa notes how beneficial the changes have been for Fred: "Before this, he was in a decline. Now, he is enjoying life a lot more."

In another situation, involvement of the SDP team helped a family obtain more flexible supports from an agency that was supporting them.

The Anderson family was working with an agency to get supports for their son, who has autism. They are legal residents of Vermont, but currently live in New York State. So, they wanted to know about using waiver supports from Vermont while living in New York State. Second, they wanted more flexibility in terms of who they could hire with waiver funds. Mrs. Anderson commented, "I found that agencies say, these are the people we can give you, these are the hours—and that wasn't fitting into our needs and schedule." One of the team's roles was to inform the Andersons of the flexibility within the waiver that they were not aware of. The family now hires their own workers, for the hours they want, and this is paid for through the waiver. Mrs. Anderson writes checks directly to some of her support workers, and then she sends timesheets to the agency to get reimbursed. Other workers bill the agency directly.

A third example of increased choice and control involved a committed guardian, who, working together with the team, agency representatives, and Division staff, assisted Carrie to make some significant changes in her life.

Carrie lived in an institution in Maryland when she met Ruth, a staff person there. Over the years, they developed a close friendship. Eventually, Ruth moved to Vermont; Carrie would come to visit a

couple of times a year and always ask to move there. In 1993, Carrie moved into a developmental home in Vermont, and Ruth became her legal guardian. At first, Carrie's services were provided through an agency. However, over time, Carrie and Ruth became frustrated since Carrie had continually expressed the desire for a job, and they felt this was not being addressed.

Eventually, Ruth described, "We said, let's cut out the middle man, we can do it better." So, they found another agency that was willing to let Ruth and Carrie manage their own services. It took a couple of months for them to figure out things like how to do payroll, the budget, and so on. They hired a private payroll service that prepares checks, quarterly tax reporting, and unemployment tax, and they had to get a workers' compensation policy. The agency holds the developmental home contract, and holds the legal risk.

Ruth now works directly with the developmental home provider to address any issues that arise. In addition, she knows the respite providers, and is in regular contact with them as well. She has worked on changes in the budget in order to use the respite money in ways that are of more interest to Carrie.

Overall, Ruth is very satisfied with the way things have worked: "In the long run, after getting through all these little hurdles in information, things have gone very smoothly...Without this grant, we

would not be able to do what we are doing, and that means a lot to us."

3. **An increasing number of people with disabilities feel a sense of empowerment.** SDP staff are clear that empowerment happens as a result of the steps that people themselves take in the process of claiming more control of their lives. The SDP has worked in collaboration with the Vermont Peer Support Network (PSN) to support people in this process (issues related to self-advocacy are discussed further in a later section of this report). An agency representative commented, "One of the teams' roles is more like empowering the person to do things for themselves."

Individual empowerment has come about in a number of ways. People who have worked with the teams to make changes in their lives expressed a sense of having more choices and greater control. SDP staff members, family members, guardians, and others also noticed changes in people. For example, one team member observed, "More people know about their money, or are asking for information about this. Now, more people are wanting to not only be involved in, but even write their own ISA (individualized service agreement)." Second, people have been empowered by working with the SDP and others to build and/or strengthen their support circles. Third, a number of people have increased their sense of empowerment as a result of involvement with the SDP doing presentations at workshops and conferences and other activities. Two stories present

different examples of people who have increased their sense of empowerment.

Margie had a long-standing desire to go to college. She and her mother started working on this with the SDP team. At the time, Margie and her mother felt that the agency that was supporting her was resistant to self-determination and would not support Margie to go to college, so they began working with an independent case manager. Margie explained that the team helped give her resources and information, and helped convene meetings, all of which led to her enrollment in college. While the team provided assistance, Margie felt that she was actively and centrally involved in the effort. She also felt that the team was helpful in listening to her mother's fears about her going to college and in helping her to deal with those.

Margie's mother reflected on Margie's experience with the self-determination team: "I can't say enough about it. It's been a big help for Margie, giving her more confidence and self-esteem, working on achieving what she wanted to do. Margie has been very inspired by her work with the project, like traveling and speaking at conferences." Margie's mother added that the team was "instrumental in educating me about Margie's money; I never knew she had a Medicaid waiver. Also, self-determination made us aware that Margie was able to decide what programs and what supports she would like."

Another person who has been empowered by the project is Helen.

The SDP team first got involved with Helen because she was interested in exploring different ways of spending her money. She has a case manager, and she had a staff person who was helping her with an "exercise program." Helen wasn't happy with this arrangement and wanted to brainstorm other ideas. She decided to take the money for the staff person and use it for a health club membership. She also wanted to reduce her case management hours from three to two, but her circle felt it was important to keep the three hours, so Helen agreed to this. After having made this change, Helen is now interested in writing her own ISA.

In the course of working toward individual change, those involved with the SDP learned a number of lessons. These include:

- **Many people want more choice and control, but not necessarily self-management.** By far, most people who have been interested in "self-determination" have not been interested in managing their own services. At one point in time, among 97 people who worked with the teams, only 7 had chosen self-management. Some of these people have never been interested in self-management. Others were potentially interested, but then decided against it when they found out about the extent of work involved. However, as a number of people who have worked with

teams have made one change, and then gone on to make other changes, it is possible that some people who are not currently interested in self-management may decide to pursue this at a later time.

- **Self-determination does not mean making choices in isolation.** Margie's mother expressed concern that, in the name of "self-determination," Margie might be left entirely alone to make all the decisions about her life. One of the safeguards to this is the presence of a support network in people's lives. For example, Helen's experience illustrates that, for her, empowerment included listening to feedback from her support circle.
- **Self-determination is a process, or series of choices and decisions.** As mentioned above, over time, project staff have found that people may start by making one change in their lives, and this may lead to a desire for further changes in their lives. For example, a team member commented about how change for Helen consisted of a series of steps: "At first she wanted to know how much money she had; now, she wants to say how she wants to spend it."
- **Self-determination is not a magic fix.** Even when people have more control and choice, this does not necessarily mean that everything always works out the way they hoped or anticipated. At

the same time, even when things did not work out very well, people still appreciated feeling more in control. As part of this, even if they felt, at times, they had made mistakes, they appreciated the opportunity to learn from their own mistakes.

- **There are some common areas in which people desire change.** Over time, SDP staff noted some commonalities in the types of changes people desired in their lives. One was the desire for a living situation of their choice, with their own space. An SDP staff member commented, "They may be in developmental homes with more than one person. For example, one person keeps reminding us he doesn't have a say in who comes and who goes, and what his environment is like." A second common issue was the desire to find real, meaningful work, based on their interests. As one staff person put it, "They want to find real work, not McWork." Related to work, another key issue was the request for support in the transition from school to real work.

Challenges to Implementing Self-Determination at the Individual Level

At the same time as there are many expanded opportunities for individuals to have choice and control in their lives, there still exist many challenges to making such opportunities available for all people with disabilities in Vermont. This section discusses some of the key challenges.

1. **There are some people who still have not had access to information about self-determination.** Everyone agrees that there is still more work to be done in getting information to people. One guardian emphasized, "Those who already have the information are the ones who have achieved what they want most readily." Some of the limitations to this were due to the time constraints and other demands on team members. Other limitations involved getting information to people where reaching them was dependent on an agency, family, or guardian. Some of those who were interviewed felt that if these people were not informed or supportive of self-determination, then they sometimes did not pass information about various options on to individuals and families.

2. **Some people with disabilities feel intimidated about expressing preferences and exercising choice and control.** There is the sense among some people with disabilities and others who were interviewed that at least some professionals would still disapprove of increased control in the hands of self-advocates. At the same time, many people with disabilities still rely on service providers for some form of assistance, so it can be difficult for them to raise issues and take actions that may put them in conflict with the service provider. If they do express desire for a change, they are concerned others may not see this as a priority, or that they may disapprove, and that this may even jeopardize their services as a whole.

3. **There is need for more technical information for families, individuals with disabilities, and members of their support network, especially regarding self-management.** There was general agreement that it was sometimes difficult for individuals and/or families and their support circie to get technical information related to things such as the logistics of self-management, what flexibility exists within Medicaid waiver services, and so on. As a guardian explained, "It's really been about having information. Some of the questions we needed to answer were: how do you do a budget, how do you get it approved, what do you need to do legally to protect yourself and the person and make sure you're within the parameters of the Medicaid federal guidelines, and things like that."

Some people felt that a shortcoming was the team members' lack of technical expertise. One agency director stated, "The teams encouraged people to voice their dreams, but there was not someone there to answer the technical questions, someone who had expertise in OSHA, wage/labor regulations, and so on." Some people felt that this was more of an issue at the beginning of the project, and that the lack of information was not just confined to the teams. As one guardian reflected, "Especially when the project was new, it was hard to get information. The team didn't have information from the division; the division didn't have information, the agencies hadn't done this before, everything was new."

4. **Opportunities for choice and control are very dependent upon the circle around a person.** Experience has shown that people's access to opportunities for more choice and control is variable, depending upon the assistance of a support network. While some people may advocate effectively for themselves on their own, often their efforts are enhanced by a support network which may include family, guardian, friend, and/or agency staff. While the SDP teams did not intend to become the "support circle" for people, they worked closely with these support circles, and at least in some cases were considered by the person to be part of his/her support circle. In the example of change in Carrie's life, it is clear that these were due to the presence of a committed advocate in her life. And, in the example of Fred, Christa feels that it was very helpful to have someone advocating for Fred in addition to herself, and that the team was "instrumental" in helping bring about these changes.

5. **There is hesitancy, from a variety of different perspectives, with regard to more choice/control for people with disabilities.** There is a combination of nervousness, hesitancy, and resistance about people with disabilities having more choice/control that comes from different groups of people for very different reasons. This discomfort is most particularly related to the idea of people managing their own services; and to a lesser extent with regard to people having more control without self-management. Most of the concerns revolve around issues such as the

amount of work involved in self-management, the potential risks associated with having more control, and the support the person has to draw on.

Some parents are nervous that if their son or daughter has too much control, he or she might make decisions that are unwise or put him or her at risk. Some people with disabilities are worried about taking steps toward more control. They sometimes feel threatened by agencies that take an "all or nothing" stance, in which the agency seems to want either total control or no involvement at all. Some agency representatives also expressed concern about people being isolated through self-determination and raised questions about what the agency's role would be in relation to this. One agency administrator questioned, "People may be isolated from getting necessary information from the system; when do agencies step back in?" Parents, agency representatives, project staff, and people with disabilities share a concern about the amount of work that might be involved, particularly with self-management, and that there might not be sufficient supports (formal and/or informal) to assist the person to deal with this work and decision making.

6. **Figuring out supports for meaningful, integrated lives for people with severe disabilities is still a challenge.** Even with the combined efforts of family, service providers, SDP teams, and other staff and advocates, it is sometimes still difficult to piece together supports for some people with severe disabilities. The mother of one young woman

commented, "I don't want her in a program off bowling or at a mall. What I'm looking for is for Martha to have more in her life than custodial care. You have to push, and it's exhausting over the years."

7. **In some cases, the length of time it takes to implement changes is frustrating and discouraging.** The process of changing the way one's services are provided sometimes was a long, slow process, entailing lots of time and meetings. As one agency director commented, "In some cases, I have seen people get excited, but then it doesn't go anywhere. It makes people hesitant to make referrals to teams." Another person stated, "People get excited about changes and working with the teams, but then implementation takes awhile, and I think this is frustrating for people." SDP staff shared this frustration about the length of time it sometimes took to help people make certain changes.

SYSTEMS CHANGE TO PROMOTE SELF-DETERMINATION

The systems restructuring by the Division for Developmental Disabilities in Vermont contributes significantly to creating opportunities for increased control and choice for people with disabilities and families. At the same time, one of the objectives of the Self-Determination Project was to work in collaboration with Division staff, agency staff and others to implement additional systems initiatives to promote self-determination, as well as to identify and address systems barriers. This section discusses accomplishments and challenges related to systems change.

Accomplishments Toward Systems Change that Promotes Self-Determination

Over the 3 years, those involved with the project made significant efforts to address systems issues related to self-determination. In doing so, they focused on both systems structures, as well as on issues related to implementation, such as assisting those who work within the system to increase their knowledge and acceptance of self-determination as well as their strategies for promoting and supporting self-determination.

1. **There is more awareness and flexibility within agencies regarding self-determination and in helping promote more choice and control for people with disabilities.** There is general agreement that there has been a shift in agencies toward being more flexible and open to self-determination. As one agency director put it, "It is more in everyone's awareness. There's less of an attitude that it can't be done. People are more open to thinking outside the box.". And, an SDP staff member commented, "So far, every provider, in some way, has embraced the concept."

This change has come about in a number of ways. Some individual staff members of agencies have worked on their own and/or together with people from the SDP to implement changes for individuals and families. In addition, SDP staff held numerous workshops, meetings, and trainings with various groups of staff regarding self-determination. Toward the end of the 3

years, especially, the teams began to focus more on meeting with various groups of people to provide information about self-determination. For example, they began doing training for all vocational rehabilitation staff; and they started meeting with case managers, as a group, at some agencies. Finally, the Division has encouraged flexibility and innovation within agencies through system restructuring efforts (e.g., ISA process), as well as through collaboration with SDP. There is the feeling, at least among some people, that, in encouraging this agency change, the Division has been cautious about not dictating to agencies. As one person put it, "The Division has tried to promote change not through bottom lines, but through example, through promoting positives." The response to some of the changes has been very enthusiastic. For instance, one agency director commented, "The ISA has been a wonderful change. It offers people more choice and control, and less fitting things in." There is also a feeling, expressed by some of those who were interviewed, that Division staff are easily accessible. As one person put it, "One can go way to the top to get answers to technical questions."

2. **There is more awareness and flexibility among some gatekeepers such as case managers, and public and private guardians, on a person-by-person basis.** People associated with the SDP feel that there has been some incremental change in the flexibility of case managers and guardians. More case managers and guardians are

making referrals to the SDP, and they are increasingly supporting people to pursue creative choices in their lives.

3. **There is more flexibility within the system to support different options.** From the outset, one of the major objectives of the project was to identify barriers in the system to more choice and control for people with disabilities and families and begin to address these. Consequently, one of the major efforts of the project, working in collaboration with the Division and others, was to create an intermediary service organization (ISO), through which people who choose to manage their money can have funds disbursed. This took significantly more time and effort than anticipated, and included bringing in consultants to help with exploration of different models, determination of an administrative rate, and so on. An appropriation was obtained from the legislature to start up the ISO, as well as to cover the back taxes for people who had been out of compliance.

Currently, people can enroll in the ISO, Alpha One, through their regional designated agency. At some point, it may be possible for people to go directly to Alpha One. As one project staff person commented, "We would love to be able to see people go directly to Alpha One; but, we're not at that point yet, we don't have the finances to do that yet." Although it is unclear how many people will choose to use the ISO, there has been a very positive response to having this available as an option for individuals and

families. For instance, one family member who was about to enroll in the ISO explained that, in using the ISO, she would no longer have to pay upfront for services and then wait to be reimbursed. In addition, she appreciated the fact that she would not have to do a lot of paperwork but could just send a timesheet to the ISO, and then they would send out checks and do the paperwork.

Work that went into setting up the ISO also helped clarify other ways for people to manage their own services without using the ISO. A guardian for someone who uses a private payroll service commented, "Before the self-determination grant, there was not a mechanism where you could manage your own services within the Division. This grant has allowed people to have control over their budget, actual control over the money, not just the budget. We know what we get every year, we know where it's going, how it's being spent, we decide it all."

There is recognition that having the ISO and other self-management options does not eliminate people's difficulties with services. One young man who uses a private payroll service has struggled, together with his family, guardian, and others in his support circle, with balancing his budget and at the same time setting up adequate supports in a setting of his choice. Although he continues to struggle with this, he appreciates feeling more in control of his services, commenting, "Even though things aren't great, I do feel like I have more control."

Challenges to Implementing Systems Change that Promotes Self-Determination

One of the major lessons of the project is how challenging systems change is, particularly systems change that calls for radical shifts in power and control. During the course of the project, much time and effort was devoted to changing some of the systems structures as well as to working in collaboration with agency staff and administrators to create opportunities for self-determination. Further efforts are needed both to continue identifying and addressing systems policies and structures, as well as to assist agencies and the service system as a whole so that self-determination becomes fully embraced and incorporated. To that end, some of the specific challenges are discussed below.

1. **There is need for support for further agency change.** While it was agreed that some staff of all agencies have embraced the concept of self-determination, it is also widely agreed that there is no single agency that totally "espouses the principles of SD as a way of doing regular business." A number of people who were interviewed felt that one problem is that people are given more choices by agency staff, but not necessarily more control. Others felt that there is still some association of self-determination with self-management, and some association of self-determination as applicable primarily to people with less severe disabilities.

The challenge is to build a common vision and practice, shared by all staff within agencies, that incorporates the principles of self-determination. People who were interviewed (from the SDP and from agencies) felt that it would be helpful to give more staff direct experience working together with others (possibly from within the agency and/or beyond) to creatively assist people with more control over their lives. In this way, staff who are knowledgeable and creative with regard to implementation of self-determination can serve as mentors for other staff within their agency and/or in other agencies. Related to this, people felt it would be helpful for agencies to network more with each other, so they could share strategies and problem solve together. As one agency director put it, "People are starting to learn, but we need to work on helping staff who are limited in their vision of what they see as possible."

2. **There is need for technical assistance to agencies.** There was also agreement among those interviewed that people in agencies need more assistance with figuring out the "nuts and bolts" of various service arrangements, particularly those involving self-management. Agency administrators still have some anxiety about losing money with self-management, although this has diminished significantly. As one parent put it, "This is threatening to them." In addition, according to another director, agencies still have concerns and questions about what roles and

responsibilities they have in relation to self-determination and self-management.

Agency representatives and others mentioned the need for further technical assistance to agencies to help them work out the logistics of funding and related issues. Although some training has been offered, directors felt the need for more. As one director commented, "We need ongoing training for people in the agency to get things implemented. There was some ISO training—but we had lots of questions, and people didn't have all the answers." Agencies wanted more training on things such as taxes, wage and labor issues, helping people switch money, what roles agencies would play, and so on. As part of this technical assistance, a number of people thought it would be helpful for agency staff and administrators to hear about examples and specific strategies that others have used.

3. **There is need for support for case managers and guardians to increase their active involvement in promoting self-determination.** Case managers and guardians play key roles in people's lives. Thus, it was felt that specific attention needs to be given to a number of areas related to case managers and guardians with regard to self-determination.

- **Increasing the knowledge of and openness to self-determination.** There is agreement that most case managers and guardians want what is best for people. At the same time, some people feel that while they currently assist people to have many

more choices in their lives, they may not be aware of further strategies for promoting increased control. In addition, some people felt that many case managers and guardians might be "cautious" or "fearful" about self-determination, particularly self-management. It was suggested that it might be helpful for case managers and guardians to gain more direct experience working with others to promote self-determination, and for them to share examples and stories within their agencies and beyond about creative strategies.

- **Viewing self-determination as a priority.** It was felt that some case managers and guardians view self-determination as a "luxury," separate and distinct from issues such as housing or work. It is, thus, important to promote the awareness that self-determination is a framework that should be integral to any and all decisions and issues within a person's life.
- **Support of case managers and guardians.** There is the recognition that case managers and public guardians have an "impossible" job, with many other responsibilities, and thus are hard pressed to find more time to spend assisting people in their pursuit of increased choice and control, particularly in situations where this may not be viewed as a top priority. In addition, private guardians may lack connections to networks of people who would

inform them about self-determination. As people with disabilities increasingly seek to gain more control in their lives, people felt that it would be important both to support case managers and guardians in their work, as well as to work with them to help them figure out new roles and relationships with individuals whom they support.

- **Expanding options for independent case management.** Since case managers are attached to agencies that also provide services, some people expressed concern that this results in a conflict of interest for case managers between the individual's interests and agency interests. There are some individuals with disabilities who have hired independent case managers. However, two related problems were raised with this. One is that there are not many people who are willing to do case management outside of agencies. Second, people with independent budgets would likely not have enough money to pay benefits for a case manager. Thus, these issues must be addressed if independent case management is going to be a real option for people.

SUPPORTING SELF-ADVOCACY

People involved in the SDP believe that it is crucial for people with disabilities to be at the forefront of change in Vermont. Thus, one of the major goals of the SDP was to support self-advocacy and to help expand opportunities for self-advocacy at all levels of decision making. This section

discusses accomplishments and challenges related to supporting self-advocacy.

Accomplishments in Supporting Self-Advocacy

The SDP intentionally designed its efforts in the area of self-advocacy to be in collaboration with the Vermont Peer Support Network. Thus, the accomplishments discussed here are a result of the combined efforts of the SDP and the Vermont Peer Support Network.

1. **There has been significant expansion and strengthening of self-advocacy in Vermont.** This has occurred due to the efforts of self-advocates and advisors associated with the Vermont Peer Support Network, self-advocates and other staff associated with the SDP, and with support from the Division and some agency personnel. There are increasing numbers of people involved in self-advocacy, and self-advocates have an increasing visibility, voice, and involvement in leadership positions on issues related to their lives and their services.

The SDP has supported self-advocacy in a number of ways. Within the regions, SDP teams have disseminated information about self-advocacy, supported individuals in advocating for themselves, and supported self-advocacy groups to form and /or expand. On a statewide level, the SDP has assisted with the annual self-advocacy conference; supported self-advocates in their quest to obtain leadership training, supported self-advocates to provide training to various groups (e.g., agency staff, public guardians,

etc.), and supported the involvement of self-advocates in legislative advocacy.

2. **There is increased awareness of and demand by people with disabilities for options for increasing their control and choice through self-determination.** To a large extent, this has gone hand-in-hand with work on self-advocacy. At the same time, through the SDP, there has also been much information dissemination—through individual meetings and workshops—about self-determination to people with disabilities. People who were interviewed spoke of many ways that people with disabilities are learning about and demanding more choice and control. For example, one agency director explained, "Agencies are increasingly being challenged by people with disabilities, who are asking more questions, who want to know about their budgets, things like that." Others observed that people with disabilities are beginning to ask not only about involvement in the ISA, but about writing their ISA; and, not only about choosing their case manager, but about defining the role of that case manager.

As part of their quest for more control, self-advocates, in collaboration with SDP staff, have been taking steps to make the system more accessible. They have compiled a booklet, oriented toward consumers, that explains the ISA and how to write it. In addition, they wrote a manual, "Navigating the System," which is also easily accessible for consumers. These products have

proven to be useful to a broad range of people in addition to self-advocates, including agency personnel.

3. **There is increased collaboration with self-advocates by other groups within the state.** The SDP and PSN have been instrumental in facilitating some of this collaboration; in other cases, state and agency personnel have initiated it on their own. The Division has increased its efforts to include the voices of self-advocates in a number of ways. Division administrators are spending time traveling throughout the state listening to the issues and concerns of self-advocates. One of the objectives, from the Division's perspective, is to make it clear "that the state values and supports the opinions of self-advocates equally as much as the opinions of providers and others." There is representation of self-advocates on Division committees. Members of the Division's quality assurance staff have begun forging more connections with self-advocates and the SDP, and are working on ongoing involvement of self-advocates on the Division's Community Alternative Specialist (CAS) teams, that review Medicaid services in each region. Some agencies have also increased the involvement of self-advocates on committees and in other agency decision making (e.g., involvement in the hiring process for a new director). Finally, self-advocates have become centrally involved in training for various groups of people, including public guardians, vocational rehabilitation staff, and others.

Challenges to Supporting Self-Advocacy

At the same time that there has been significant expansion and strengthening of self-advocacy in Vermont, there still remains much need for continued work in this area by everyone.

1. **There is need for more support of self-advocates/self-advocacy groups**. A number of people identified a need for more support of self-advocacy, particularly local self-advocacy groups. In different ways, the designated agencies are supporting self-advocacy groups in their regions. While this is important, at the same time, it is important to guard against self-advocacy groups becoming too closely linked to service providers, so that this does not pose a conflict of interest for self-advocates and those who support them. Some agencies are, in fact, questioning what their role should be. For instance, one agency director reflected, "Our agency could do more to promote and support self-advocacy, but how much could we do before it is not self-advocacy?"

2. **There is need for further outreach to extend access to self-advocacy.** This includes developing strategies to reach people living with families or supported by agencies that do not give them information about self-advocacy. People who were interviewed feel this may be either because families and agencies feel threatened by the idea of self-advocacy, and/or because they believe that the individual is not "capable" of self-advocacy. Outreach to extend access to self-advocacy also must entail attention to the

support some people may need in order to participate in self-advocacy. Transportation was a primary concern that was raised.

3. **It is important to work toward a point where it is routine, among the Division, agencies, and other groups, that self-advocates be centrally involved in decision making and leadership positions.** While the participation of self-advocates in such roles has increased, it is important that this becomes a regular occurrence, and that self-advocates are included on a routine basis, and not just in specially created ways. In addition, it is important that this participation be meaningful. One administrator emphasized that "to provide meaningful opportunities for input is going to take some time and effort." Some people who were interviewed felt that there is still some resistance to leadership roles for self-advocates; for example, SDP staff felt that some of the providers were resistant to the idea of self-advocates being part of provider training. Where there is resistance, and where participation is not occurring, there needs to be a clear message from the Division, from self-advocates, and from other allies that this is now an expectation in Vermont.

4. **There is need to make it "safe" for people to speak up.** As has been previously mentioned, some people with disabilities still feel threatened by agencies if they speak up. The SDP and PSN have a commitment to work together to address this; the Division has made this a priority area, as well.

SDP IMPLEMENTATION

This section focuses on some of the accomplishments and challenges related to implementation of the SDP itself.

Accomplishments Related to Implementation of the SDP

The implementation of the project offered many contributions, both philosophically and practically, that are important not only in and of themselves but it terms of their applicability much more broadly to bringing about change.

1. **The SDP emphasized a broad definition of self-determination, inclusive of all people with disabilities, including those with the most severe disabilities, and inclusive of many types of choice and control.** It was important that, from the outset, the project took the view that self-determination applies to all people with disabilities, and that it is not just about "self-management" of services, but about having more choice and control. As a member of one team put it, "Self-determination is not just all or nothing. It includes every little piece of change, every step a person might take." Another person commented, "We haven't thought about it just in terms of self-managing services, but in terms of lots of different ways people can take more control."

2. **Through its triad model used as the basis for composition of the project teams, the SDP demonstrated effective collaboration between people with disabilities, family members, and provider**

representatives. In implementing the project, the staff have demonstrated the power of collaboration between people with disabilities, family members, and service providers. Throughout the course of the project, there were a number of key factors that contributed to positive collaboration on teams.

- **Commitment that all members of the team would be part of all project/team activities.** Without this commitment, at times it might have seemed "more convenient," for example, because of access, time, or whatever, for only the two nondisabled team members to be involved in some of the activities.
- **Commitment to respecting one another and changing preconceived notions**. It was important that team members be willing to learn from one another and not make stereotyped judgments of one another (e.g., as family member, consumer, service provider).
- **Commitment to ongoing work on communication**. It was important that team members continually work on their communication with one another. This meant things such as giving each person a chance to speak, listening, respecting differences of opinion, and the willingness to be open about communication problems and work to address them.

- **Commitment to support consumer participation.** The support of consumer facilitators was integral to the overall functioning of the teams as a whole. This issue is discussed in further detail below.

For project teams, working together included many positive aspects as well as many struggles. The willingness of the teams and the project staff as a whole to work together to address difficulties was a key to their overall success. They felt that how they worked together was equally important as what they did together. As one team member put it, "The project is as much about who it is that we are together, and how we do stuff, as it is about what we go out and do." The work of the project teams serves as an illustration that this kind of collaboration is possible and effective. It serves as a model for the types of commitments required of all people within the state if true inclusion of people with disabilities in all aspects of services is to be achieved.

3. **The project made significant efforts to figure out the most effective way to support the consumer facilitators on each team.** Support can be a key factor in the participation of people with disabilities in community groups and organizations. From the start, the project wanted to ensure that there be sufficient, quality support for consumer team members. They wanted to ensure that the three team members could relate to each other as peers, and that the nondisabled team members were not put in the

position of having to relate as supporters. Funding was provided so that each consumer facilitator could have a job coach; these people were hired individually, by each consumer facilitator, through a service agency. In addition, soon after the project was started, they identified the need for a project staff person who provided additional support to the consumer facilitators, and support to the teams as a whole in including the consumer facilitators. A strength of the project in its support of consumers was the flexibility to change the supports offered to consumer facilitators, based upon their needs and desires.

4. **Over the course of the 3 years, teams and other project staff worked collaboratively with many different individuals and groups representing diverse constituencies.** At the beginning of the project, it was acknowledged that collaboration among the SDP and many constituencies in Vermont was essential if real change was to occur. As a result, project staff made many efforts to collaborate with others.

A primary emphasis was placed on collaboration with self-advocates, particularly through the Vermont Peer Support Network. As one staff member commented, "We've had a true collaboration of project staff with self-advocates and the PSN. We are so much further along than we were a few years ago...The project never sees itself as an entity alone."

In addition, the project staff worked collaboratively with the Division, with agencies, and with schools, among other groups. There has been a high

degree of support for and collaboration with the project by the Division. There was ongoing interchange between the SDP and Division staff during both project and Division meetings. In addition, Division staff and administrators worked collaboratively on many of the project initiatives.

Teams and other project staff also had a great deal of contact and sometimes collaboration with provider staff and administrators. This involved efforts related to particular individuals and families, as well as occasional activities such as workshops, trainings, and the like. The degree to which participants sensed a real spirit of collaboration varied from agency to agency, team to team, and person to person. From the point of view of agency administrators, at least some of this collaboration was positive. For instance, one director stated, "Some teams have had a lot of contact with agencies that has been very positive." Another director commented, "There are some wonderful examples that have been created within the agency; staff are working more with the self-determination teams, and there are more referrals to teams."

Finally, some of the teams focused on making connections in schools. One team developed a self-determination "curriculum" targeted to school students. Another worked to establish a "Best Friends and Advocates" program at a local high school. A number of people agreed that the area of schools, and transition, is important to address more fully in the near future.

5. **Staff of the project demonstrated a very high degree of commitment to their work.** The project attracted very committed, dedicated staff. They were committed to building positive relationships with each other, and with those with whom they worked. As a staff, they worked hard on getting to know each other, listening to each other and sharing similar and divergent perspectives, and celebrating together. Individuals and families that they worked with saw them as accessible and trustworthy. The developmental home provider for one person the team worked with commented, "The team was always accessible. They gave Fred time to get to know him and to establish comfort." Another person, a parent of a person who worked with a team, commented on how she most valued their trustworthiness. In addition, she appreciated knowing that they had her daughter's "best interests" in mind. "The most important thing is trusting people you work with; you have to be able to trust them—that they would have Margie's best interest in mind."

Challenges Related to Implementing the SDP

There were some aspects of project implementation that were particularly challenging. These, as well as the accomplishments, have a role to play in serving as broader lessons about change.

1. **Staff of the project had to dealing with their own differing approaches to systems change and, more broadly, to societal change.** The teams and project staff as a whole had to struggle with

different ideas of how to go about changing the system, and, more broadly, promoting societal change with regard to people with disabilities. For example, project staff had differences of opinion about how to balance their roles of working collaboratively with agencies and other professionals versus advocating vis-à-vis these agencies and professionals on behalf of families and people with disabilities. In addition, some people felt that the best way to create change was by working with the system to change it, whereas others felt it was most important to work around the system. These kinds of differing viewpoints created tensions and required discussion that was not resolved with "right" or "wrong" answers.

2. **Teams and the project staff as a whole struggled with support for the consumer facilitators**. There were a number of issues that came up regarding support for the consumer facilitators. Some of these issues related to the job coaches who were hired by the consumer facilitators to assist them with their work. Other issues related to the role of other team members vis-à-vis the consumer facilitator. Both are discussed below.

Job coach issues. Over the course of 3 years, consumer facilitators had as many as six or seven different job coaches for their project work. This is reflective of the high rate of turnover among direct service staff. This meant that consumer facilitators spent a considerable amount of time and energy training and adjusting to new people. The team as a whole also had

to deal with different styles and personalities. Due to unreliable transportation and other supports, consumer facilitators were sometimes late to meetings and other engagements. This also had an impact on the team as a whole.

Consumers facilitators and teams struggled with figuring out the role of job coaches (e.g., in relation to the role of personal care assistants, the project staff person who provided support to the consumer facilitators, and the other team members). Consumer facilitators and the teams as a whole also struggled with how to involve the job coaches. When job coaches attended meetings, they sometimes did a lot of speaking for the consumer; but, when job coaches did not participate at all, some of them felt disconnected from important information and communication. As a result, teams, and the project staff as a whole, tried out different arrangements to see which would work best for which individuals and teams.

Finally, some of the job coaches were from agencies that have designed job coach services to be faded out as the person gains skills. This service design does not work for those individuals with disabilities who need ongoing assistance. In some cases, the consumer facilitator was able to negotiate with the agency to provide ongoing support. However, this points to an area that needs to be addressed on a system-wide basis, so that such ongoing supports are routinely available for those who need them.

General team issues. In terms of the relationship of other team members to the consumer facilitators, the vision of the project was that all would be equal partners and co-workers on a team. In principle this included the idea that team members would not be in the position of having to provide support for the consumer team member. However, the real experience working together was not as clear cut as this. Sometimes when the consumer facilitator was without support, other team members stepped in to help out. At other times, when the consumer facilitator was having difficulties in his or her own life, team members offered suggestions and advice. They did these things based upon mutual, caring relationships that had evolved out of working on a team together. Teammates without disabilities struggled with when or whether to step in. At the same time, consumer facilitators learned to set boundaries with their teammates in relation to these issues as well.

3. **The teams and project staff found that collaboration with agencies was sometimes challenging.** From the beginning of this project, one of the objectives was to create dialogue and collaboration with agencies. And, to some extent, this occurred. At the same time, some project staff who were interviewed felt that this networking with providers did not receive as much attention as was originally intended. From their perspective, this was not due to lack of interest, but was a result of concentrated efforts in other areas (e.g., outreach to consumers, families,

working on other systems change issues). As part of this networking, some people (project staff and others) felt that there could have been more identification and acknowledgement of supports that are already being provided by agencies in ways that give people choice and control. At the same time, some of those who were involved with the project were frustrated at what they perceived to be agencies' resistance to change. As one consumer put it, "Agencies need more awareness of and openness to self-determination." Increased collaboration between agencies and others involved in working on self-determination will make a significant contribution to enhancing the quality of lives of people with disabilities in Vermont.

4. **It was difficult to accomplish the work of the project in the time available.** There was widespread agreement among project staff that 20 hours per week was not enough time for all the work they had to do. With significant distances to cover, people spent a large percentage of their work time traveling to and from meetings. Throughout the course of the project, various means were utilized in an attempt to address this, including having fewer meetings, rotating meeting locations, and so on. While some of these attempts helped to one degree or another, none completely addressed the problem. Because of the time pressures, in combination with the many different project activities, a number of staff felt that it was challenging to prioritize their activities.

Similarly, there was a sense that the project director's work might have been facilitated by using one and a half or two people. "Supervising staff was a full-time job; then, on top of that, were a wide variety of administrative duties (e.g., associated with ISO trainings, designated agency contacts, and so on)."

Finally, while the staff meetings were an invaluable source of information and networking for project staff, there was not enough time to cover everything that people felt should be covered. For example, at least some staff felt they could have used more time for sharing stories, strategies, and problem solving.

NEXT STEPS

There is agreement among those interviewed that significant progress has been made toward more choice and control for people with disabilities in Vermont, and that the SDP has made major contributions to this. At the same time, there is both recognition of and frustration with the slow nature of change and the many challenges that still lie ahead. However, it is the accomplishments and successes of the project that have helped identify and clarify what the next steps are. Based on the interviews, some of these priority areas that people identified are briefly described below.

Planning for SDP itself: It has been clear from the start that the SDP itself would not necessarily always continue to exist as a grant funded initiative. Therefore, since its inception, project staff focused on their roles

of facilitating change, collaboration, and capacity building, so that they would not create a permanent reliance on the project. While much has been accomplished toward these ends over 3 years, there is widespread agreement that much more work remains to be done, and that there is still a need for the energy and resources of an entity such as the SDP. At the same time, the specific activities and structure of the SDP need to be reevaluated based upon lessons learned and other next steps that have been identified. Therefore, planning for this continuation of the SDP is an important priority.

Pay and benefits issues for direct service staff: Recruiting and retaining direct support staff is a critical issue for agencies as well as for people who hire their own staff. Addressing pay and benefits issues would be a step toward dealing with this problem.

Development of new providers: Individuals and families still have little choice of agencies, particularly in more rural areas of the state. One of the barriers to this is the lack of a certification process for new agencies. Therefore, this is a key next step toward promoting more choice and control for people with disabilities and families.

Expansion of and support for self-advocacy: Self-advocacy plays a critical role in enhancing people's opportunities for increased self-determination in their lives. In addition, in order to create a system of services and supports that reflects the principles of self-determination, it is essential to have the active participation, in all levels of decision making, of

people with disabilities. Expansion of and support for self-advocacy was a key priority of the SDP. However, this is an enormous task. Thus, despite the progress that has been made, there are still many people in Vermont who do not have information about or access to self-advocacy. In addition, there is need for increased support for self-advocacy, on both an individual and a group level. Thus, it is agreed that continuing efforts are needed in these areas.

Schools/transition: School and the transition from school to work and meaningful daytimes are critical times for young people with disabilities and their families to learn about choice, control, rights, self-advocacy, decision-making, and many other aspects of self-determination. During the course of the project, it became clear that there is need to direct more energy toward bringing opportunities for self-determination to children and families in schools and as they transition out of schools.

Individual budgets: Vermont has been a leader, nationally, in its use of individual budgets. At the same time, people with disabilities were not typically involved in the creation of these budgets. Therefore, people who were interviewed feel it is time to take the next step of involving those with disabilities and families in creation of the budgets.

Increased development of flexible, individualized supports: While Vermont, again, has been a leader in the development of individualized supports, there are still gaps in services for some people with

disabilities. For instance, based on the experiences of the consumer facilitators with job coaches, there is need to develop supports that are based on need, and are not necessarily time-limited. Second, based on the experiences of some individuals with severe disabilities and their families, there is need for further availability of supports that promote inclusion and meaningful lives.

Continuing information and education about self-determination: Project staff devoted significant effort to raising awareness and knowledge about self-determination. However, as with self-advocacy, this is an enormous task, and there are still many people who do not have much, if any, information about self-determination or who have misinformation of confusion about it. Others are aware of self-determination, but desire more detailed information about putting it into practice. Thus, continued information about self-determination needs to be disseminated to all constituencies, including the Division, all levels of agency staff, guardians, families, advocates, and community members.

Collaboration with providers: Collaboration between providers and all others is essential in order to promote increased choice and control. From the outset, a primary aim of the SDP was to establish collaborative relations with providers, and to facilitate increased collaboration between people with disabilities, families, and providers. Although there has been

some collaboration between providers, project staff, people with disabilities, and families, it remains a priority to work toward increased collaboration.

Positive practice and mentorship: While many people now know about self-determination, some of these people still could use creative ideas and strategies for implementing it. In order to do this, significant emphasis was placed on the need for sharing stories and strategies that highlight positive practices and creative strategies. One approach to this could be through mentorship at all levels of the system, as well as among people with disabilities, families, and advocates.

Transportation issues: For years, people with disabilities have been raising transportation as a major barrier to any kind of community participation. Still, today, it is continually raised as an issue. It is important that people look for creative ways to address this, and that agencies, the system as a whole, and communities be willing to invest resources to address it.

Relationships and support networks: It was clear from the project work that people needed relationships and social networks that valued and supported their right to choice and control. Such relationships play a significant role in people's access to services, their choice and control of these services, their safety and well-being, and their general quality of life. Therefore, this needs to be a priority area for agency staff, advocates, and others.

CONCLUSION

From the start, people involved in the Vermont Self-Determination Project have been clear that in order to make the opportunity for self-determination available to everyone, it is essential that there be radical, comprehensive systems change. They were also clear, from the start, that such systems change would be a monumental effort, involving, at its core, a fundamental shift in power and control, from the service system to people with disabilities and families, and necessitating a radical shift from past attitudes, perceptions, policies, and practices toward people with disabilities and families; a shift that would be uncomfortable and frightening for some if not many people.

They recognized, as is clear from the design of the project, that such systems change would necessitate a multipronged approach. Thus, the project focused its energies on a number of key areas:

- Contributing to change in power and control in the lives of some individual with disabilities.
- Contributing to change in systems structures and funding mechanisms
- Supporting and advocating for people with disabilities and families in the quest for more control and choice at the individual and systems levels

- Providing education and resources that contribute to understanding of and creation of systems change that promote true choice and control
- Building and strengthening coalitions and collaboration between different constituencies, with inclusion of people with disabilities and families as central to this

Over the course of 3 years, through these focus areas, the Vermont Self-Determination Project has made a significant contribution to comprehensive systems change. At the same time, it is clear that 3 years is just enough time to lay the groundwork for change. The experiences of the project illustrate both the power of such changes, as well as the tremendous challenges involved in creating fundamental shifts in attitudes, policy, and practice, and in doing so in true collaboration with self-advocates and families. Thus, continued efforts in these focus areas, and on the issues identified specifically as next steps, are critical and key to building the capacity of the system in Vermont to become one that supports real choice and control for all people with disabilities.